Mental illness: A difficult diagnosis with sometimes deadly consequences

By Anna Griffin, The Oregonian
updated March 02, 2013 at 11:11 PM

From the Desk of
Senator Brian Boquist

When something as horrific as the Sandy Hook Elementary shootings occurs, human nature tells us to seek rational explanation, to ask why. That question doesn't get us very far.

"I don't think anybody is an expert in this kind of thing," said Bonnie Nagel, a neuropsychologist at Oregon Health & Science University. "It dumbfounds us all."

A few strands of connective tissue tie the nation's recent mass shootings together. Gun access is one. Mental health is another.

In many massacres, the killer was a young man in his late teens or early 20s. He either suffered from a mental illness or exhibited symptoms of one before he killed. Even Clackamas Town Center shooter Jacob Roberts, though never diagnosed with a mental illness, behaved like a person grappling with depression and suicidal notions before he opened fire outside Macy's. He sold his belongings, quit his job and told friends he was leaving Portland for Hawaii.

"There's one commonality in most of these cases: They want to die," said Portland social worker Mark McKechnie.

That reality leads to other, better questions: How do we reduce the chances of another Virginia Tech, Aurora or Newtown? Are we doing enough to help young people, particularly young men, control their anger and manage their own mental health care?

Neuropsychologist Bonnie Nagel
On this point, experts understand. Millions of children don't receive the mental health support they need. Those with potentially severe mental illnesses, the type that can morph into something deadly as adolescence evolves into young adulthood, aren't diagnosed early enough. They're not getting the compassionate, thorough care that will help them make smart decisions once they reach the age of consent.
"It makes me uncomfortable to sound like I'm on the same page as the NRA," said Dr. Stewart Newman, a Beaverton psychiatrist. "But we have to look at access to mental health if we're serious about modifying risk. Will it stop the next Adam Lanza? No. Will it improve lives? Absolutely."

MRI research

Scientists know what mental illness looks like. But researchers cannot pinpoint what in the complicated mix of tissue, blood vessels, synapses and neurons leads two people with the same basic hardware to go in radically different directions.

"Parents will say to me, 'Can you do an MRI of my child and tell me what's going on?' No. We're not there," said Nagel, an OHSU researcher who specializes in the development of adolescent brains. "We're not near the point where we can look at one kid and say, 'bipolar,' or 'schizophrenia.'"

In a typical study, Nagel and colleagues conduct MRIs on 300 or so 12-year-old test subjects, then follow up every few months to see whether the children have begun using drugs or alcohol or feeling depressed. They compare the MRIs from healthy children to those with mental health problems in the hope of identifying differences. Her team also uses DNA and hormone samples.

"Part of the challenge is that we're waiting on human nature to evolve," Nagel said. "It's not like an animal study in which we can manipulate scenarios. We have to wait for things to happen."

Child psychiatrists don't struggle to explain the elements that create a killer: "A critical absence of empathy and a critical lack of self-regulation," said Dr. Ajit Jetmalani, director of OHSU's child and adolescent psychiatry division.

Those are injuries that a doctor can diagnose, somewhat like cancer or a broken bone. But cancer is caused by cells multiplying, and a broken bone comes from blunt trauma. A lack of empathy can stem from so many potential sources: Was the patient abused? Did his parents' divorce hit him especially hard? Is his brain missing a certain correct mix of chemicals?

Figuring out how much of a mental illness is environmental and how much is biological helps determine the best course of treatment, say how much of a doctor's time should be spent finding the best possible medication vs. guiding the patient through talk therapy. Precise answers are a long way off: 10 or 20 years, Nagel says, not one or two.

"And I suspect it's always going to be more subtle than, 'Here's the sign of a kid in trouble. Here's how we know this is one to worry about,'" she said.

Mental health in children

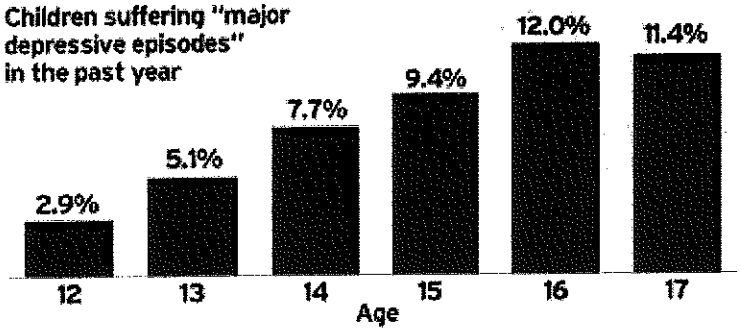
Scientific studies and anecdotal research both show that adolescents are more likely to suffer mental health problems than adults, and that the middle school and high school years are a prime time for depression and suicidal thoughts.

Those who reported some kind of depressive incident:

8.2% of all 12 to 17 year olds

12.1% were girls

4.5% were boys

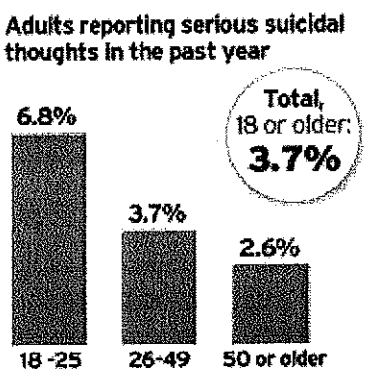


Source: 2011 National Survey on Drug Use and Health

DAN AGUAYO/THE OREGONIAN

The young adult danger zone

The "young adult" years, from around 18 to 25, are considered the danger zone for people with mental illness. A coalition of Oregon psychiatrists say federal and state privacy laws, which make it difficult for doctors to share information about a patient's care with parents, increase the risk at an already tumultuous time.



Source: 2011 National Survey on Drug Use and Health

DAN AGUAYO/THE OREGONIAN

The teen years

Many mental illnesses that peak in a person's 20s begin to emerge in the teenage years. That's a time of dramatic physical and psychological changes for every child, posing another problem fending off future Newtowns:

How do you differentiate between normal adolescent angst, short-term stress and true, long-term mental illness that could turn a troubled youngster into a dangerous young man?

"This is the transition between childhood and adulthood. It's the first time the stakes are very high for kids, the first time grades matter, the first time they can do permanent damage to their records. And they're all going through all of these changes," said Sarah Turner, the seventh-grade counselor at Evergreen Middle School in Hillsboro.

Schools have kids from 8 a.m. to 3 or 4 p.m., longer than many working parents see their children awake during the week. Administrators, teachers and counselors are often the first to spot signs of trouble, to identify an Adam Lanza or Jared Loughner in the making.

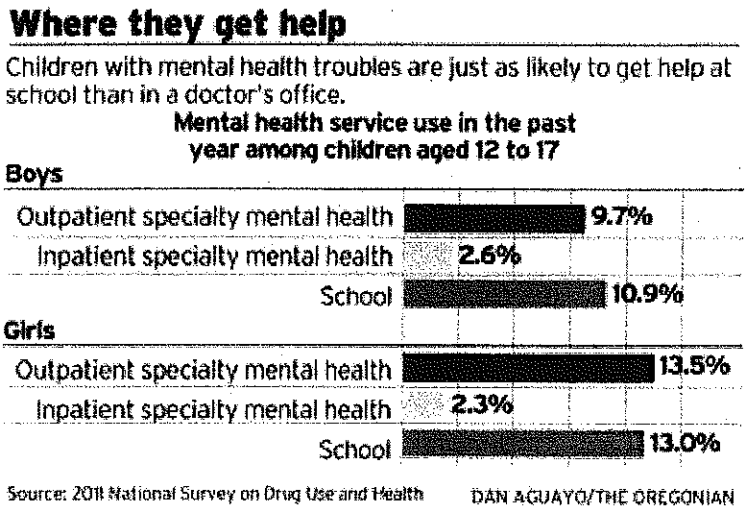
That's harder than it sounds, particularly given the differences between boys and girls. Girls often express their distress in more obvious ways. They're also far

less likely to turn out to be killers.

"Base rates of depression are far higher in females than males. Is that really the case? Or are we just better adept at diagnosing in females?" said Nagel, the OHSU researcher. "We don't like to talk about sex and gender issues in mental health, but there's clearly something we've been remiss in not considering."

Turner and other school counselors and teachers say that during the past decade, their conversations have turned more toward the challenges facing boys.

"It's become really evident that we haven't set up our schools in a way that leads to success for boys. Boys are tactile, they need to engage and be moving," she said. "We haven't quite figured out how to structure schools in a way that maximizes the learning experience for boys and also helps us identify which ones may be suffering from something that requires care."



In schools that are as overcrowded and underfunded as many in Oregon, simply keeping order becomes the priority.

"We're a school of 800 kids, with classrooms that are anywhere from 34 to 37 kids. If you have two or three kids whose behavior is bubbling up, is external, those are the ones who are going to get the attention," Turner said. "You might not notice that you have a quiet kid who may have something very troubling going on under the surface."

In other words: The chair throwers get attention. The "internalizers" may not. Sometimes not until it's too late.

Assessing threats

Will Henson watched coverage of Newtown knowing that his phone was about to ring off the hook. He's a psychologist and special education consultant who works with school districts to assess potential threats and minimize risk.

Join reporter Anna Griffin for a live chat about this story at noon Monday.
His is a growth industry.
"It takes something like Newtown or Clackamas Town Center to make us all suddenly aware of the risk. That kid who seemed kind of vaguely creepy last week seems like someone you want to get help this week" he said. "We focus a lot on what I call 'day of' -- people jump to talking about limiting access to guns or putting armed guards in schools. I wish we had more conversations about crisis assessment before someone is actually in a crisis, because the system would look very different."

Henson recommends creating a broad network of adults to keep an eye on kids, and a well-defined, well-understood system for identifying true threats.

"Every kid out there who plays violent video games says things that don't sound good. We have kids who make hit lists when they're angry. Boys in particular love to draw guns, violent pictures, talk about the violent movies they've seen," he said. "I often find it more useful to go to a staff and tell them which risk factors we're not seeing. I can say, 'We've got no history of violence, no recent losses or major life stressors, no history of threats,

a stable home life with supportive adults, no access to weapons. So I'm not seeing the kind of risk factors I'd be really worried about.'"

In Oregon, Hillsboro offers a model of the group approach experts such as Henson suggest. Seven years ago, the school district won a $9 million, three-year federal grant aimed at bringing public and private agencies together to better identify kids in need.

One way they do that is through attendance figures. A child who misses too much school gets put under the supervision of a "Care Team" that includes administrators, teachers, police officers, psychiatrists and social workers. They work with the student and his parents to figure out why the child hasn't been attending.

"What we found early on was that so many of the kids who were missing a lot of school had underlying mental health issues," said Leslie Rodgers, a social worker and care coordinator for the district. "Kids don't just stop going to class. They were being bullied, they were anxious about their work, they were depressed to the point that they couldn't get out of bed. Or their parents had their own mental-health problems and didn't notice what was going on with their child."

Rodgers and her coworkers meet with families, often at home rather than at school. They hold workshops for teachers: "We still have teachers who say, 'Suicide? I can't even mention the word in front of the class, because I'll give them ideas,'" Rodgers said. And in general, they try to create an atmosphere in which every adult feels responsible for keeping an eye on every child, even the quiet ones.

It's working. During the three-year grant period, attendance improved districtwide. Fewer dropouts meant more revenue, and Hillsboro leaders have continued to find money to pay for Rodgers and her colleagues. Yet every January, when budget-cutting season rolls around, they worry.

"We have jobs because we took mental health outcomes and tied them to attendance. Otherwise, how do you measure mental health? What are the statistics you use to prove that you've created a more positive, safer school culture and should thus stay employed?" she said.

Assigning a dollar value to mental health is a challenge for everyone. At OHSU, Nagel's grant applications often focus on targeting early indicators of drug abuse and alcohol addiction, not other mental illnesses. It's much easier to win research money for addiction, in large part because it's easier to calculate the financial costs of drug and alcohol abuse.

A big part of Rodgers' job is serving as a parental conduit for information and contacts. When the file of a high-needs kid hits her desk, she says a silent prayer that the child's family qualifies for the Oregon Health Plan. "If they're on public insurance, I know I can at least guarantee them access," she said. "If they're privately insured, it could be a couple of months before they even get in to see a doctor."

Federal and state regulators have pushed "mental health parity," since the 1990s. Laws now require insurers to offer some mental health coverage and prohibit them from placing limits on psychiatric care -- say co-pays or caps on how many hours of therapy a patient can receive -- that go beyond those on medical and surgical coverage.

Still, middle-class Americans struggle to find doctors and persuade insurers to pay for care. Private companies insure a majority of Americans but account for only a quarter of what we spend each year on mental health, according to a 2011 Kaiser Family Foundation study.

The problem: Mental health care is different from other forms of medicine, yet the business model is the same. Billing codes and billable hours drive treatment.

"Insurance companies do not pay me to get on the phone and talk to a school counselor or a social worker. They don't pay me to stop at a patient's house to make sure a young man understands the reasons he needs to take his pills," said Newman, the Beaverton psychiatrist, who practices at Mind Matters, which was founded to serve middle-income families that don't qualify for public insurance. "There's no billing code for continuity of care."

The result: Simply finding a doctor, let alone one who'll provide nuanced, individualized, all-hours care, can be tough. Ninety-million Americans live in federally designated "mental health professional shortage areas," a far greater need than dentists (45 million people) or primary care physicians (57 million). A recent study estimated that for every child psychiatrist working today, the United States needs two more.

"I want to be able to get a referral from a pediatrician who is worried about a child on Friday and say, I can see you Tuesday morning," Newman said. "Right now, the best I can usually do is, 'I'll see you in three weeks.'"

Such lags can have fatal consequences for children with long-term mental health needs.

A child whose initial experience with the mental health care system is frustrating or uncomfortable is less likely to maintain that treatment when they turn 18, the magic number in our mental health system. After that, federal and state privacy laws prevent doctors from sharing information about a young adult's care and condition unless the patient has signed a release or the doctor believes there is an "imminent threat."

Many doctors and counselors interpret that to mean they cannot share any information with parents, even in cases in which a mother or father has been intimately involved in a child's care up to that point. Medicaid statistics show that mental health spending increases each year for children as they approach 18, then falls off sharply. Spending picks up again at 25.

"A lot of these shooters are between 18 and 25," said Jetmalani, the head of child and adolescent psychiatry at OHSU. "That's not a coincidence."

Leaders in the Oregon Psychiatric Association, the Oregon Council of Child & Adolescent Psychiatry and the National Alliance on Mental Illness want to convince other doctors and public institutions to broaden the way they interpret HIPAA and other privacy laws. Jetmalani and Newman, among others, say their profession should err on the side of averting tragedy rather than protecting confidentiality. They're working with Jerry Gabay, a Portland activist and former lawyer who has a painful and deeply personal understanding of why 18 matters.

Doctors first diagnosed his daughter, Susanna, with major depressive disorder at 17. She was hospitalized for a psychotic episode in the spring of 2010, while a junior in the honors program at the University of Oregon.

During that stay, she signed a disclosure form allowing doctors to talk to her parents. But Gabay and his wife had no idea how much distress she was in, and doctors did not seek their help when Susanna refused to try a new medication.

A month later, she committed suicide.

The mothers who meet every other Sunday afternoon at the Providence Child Center in Northeast Portland hear the clock ticking. The legal barriers that arise at 18 come up at almost every gathering of Talk It Over, a support group for parents of mentally ill children. It's one of the realities longtime attendees slide across a hospital conference table to new arrivals along with tissue boxes and tubs of Silly Putty to squeeze as stress relief.

Among support-group members, the Newtown killings didn't prompt cries of "why." These parents know the basic elements of tragedy: A troubled kid didn't get the help he needed. He grew into a troubled young man.

Something set him off, turning all the worst-case scenarios they lay awake at night fearing for their children into a horrible reality we all share.

"See this?" Erin Quinton, a school teacher like Adam Lanza's mother, slaps a thick blue binder she carries almost everywhere. The three-ring notebook bulges with a collection of doctor's bills, patient notes, emails, letters and phone messages Quinton has collected. "This is my life."

Quinton bristles when news accounts refer to the 26 people who died in the Sandy Hook massacre. There were, she notes, 28 lost souls -- if you count Lanza and his mother.

"I call myself an advocate for my kid, but the truth is that I'm a pain in the neck, a note-taker, a list maker, somebody who takes every single piece of paper that has to do with my child and files it away in case I need it one day," Quinton said. "You start to feel kind of crazy yourself."

Her story is typical: Early warning signs -- blank stares, a lack of empathy, social struggles -- blossomed into something worse as puberty hit. Now she knows the difference between a child taking his or her medication and one who has stopped: "It's the difference between a text asking me how I am and one threatening to kill me. It's not subtle."

She's taken the seemingly extreme step that moms at Talk It Over routinely advise one another: When all else fails, call 9-1-1.

"It sounds horrible doesn't it?" said Margaret Puckette, who founded Talk It Over to help pass along lessons she learned with her daughter. "But think about the worst-case here: your child is bigger than you, so you can't force him to take his medication. He's on a waiting list for a hospital bed, but it's going to be a week or two. In the meantime, he's home, untreated, refusing help and threatening you.

"Sometimes, given all the problems with our system, calling the police is the only way to get help."

You do what you have to do. To protect your kid, yourself and everybody else.

http://www.oregonlive.com/health/index.ssf/2013/03/mental_illness_a_difficult_dia.html